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## **Moral pioneers: Pakistani Muslims and the take-up of assisted reproductive technologies in the North of England.**

*Bob Simpson, Mwenza Blell and Kate Hampshire.*

Dialogism argues that all meaning is relative in the sense that it comes about only as a result of the relation between two bodies occupying simultaneous but different space, where bodies may be thought of as ranging from the immediacy of our physical bodies, to political bodies and to bodies of ideas in general (ideologies) (Holquist, 2002: 21).

### **Moral Pioneering and ARTs**

What are the ethical issues faced by British Pakistani Muslims when they contemplate the use of ARTs in the face of difficulties conceiving a child? Are there particular areas of friction and sensitivity which might inhibit access to otherwise widely available treatment? These were the key questions we set out to answer as we embarked on research into the use of ARTs by women and men from this community. At the outset, our question was one that Morgan Clarke has characterised elsewhere in this volume as follows: “Is X allowed in Y?” where X stands for a controversial medical procedure such as, for instance, abortion, and Y for a religious or cultural tradition, as for example ‘Islam’, which, it is felt, needs to be taken into consideration, more or less seriously, for the proper formulation of policy, governmental or clinical’ (Clarke, this volume). In the research we expand on here, ‘Y’ is a community of

Pakistani Muslims living in an industrial town in the North-East of England who share a country of origin and profess the same religion. 'X' is a novel and a potentially ethically challenging medical intervention (IVF) into a condition of common concern (infertility). Along with Clarke, we have found this widely used formulation, and the resulting invocation of a singular 'Islamic bioethics', to be a crude one. The community we encountered did indeed have markers of ethnicity and shared attributes of culture but the level of engagement and shared intimacy which the topic of infertility generated resulted in far greater texture than is revealed by the 'is X allowed in Y' question (also see Hampshire et al 2012a, b). Indeed, as we go on to demonstrate here, the content of our interviews and interactions caused us to question ideas of the clearly bounded and homogenous communities that are often implicit in the methodologies used to study ethnic minorities in plural societies (cf Shaw and Chattoo this volume). In our interviews we were struck by the way that the responses we received were strongly influenced by generational, educational, familial, and occupational factors.

Furthermore, reflection on reproductive narratives suggests other limitations to the 'is X allowed in Y' question. The ethical framing of ARTs does not happen in a single moment nor does it suggest a linear trajectory which results in simple acceptance or rejection. On the contrary, the engagement with ARTs for this community, as for any other, is kaleidoscopic in the sense that patterns of ideas and attitudes change according to what people think, what they think others think, what they think others think about what they think and so forth. This approach takes us far from a clear set of prescriptions for action and into the fluid and contingent nature of decision-making when suffering is situated in moral worlds. As Inhorn has pointed out at the beginning of this section, these moral worlds are not 'local' in the sense that

Kleinman (1992 and 1997) proposed. Moreover, they are shot through with the influences which come from overarching structures of health care, education and welfare and through which minority groups become, to greater or lesser degrees, woven into the fabric of western states and economies.

To draw attention to these exchanges as they arise in the context of interviews and discussions opens up novel ways of bringing together anthropology, ethics and rhetoric. Rather than considering ‘attitudes’ and ‘opinions’ as fully formed and final ‘monologic utterances’ (Bakhtin 1981: 270), we draw attention to reflection, deliberation, reasoning and argumentation and the role that a variety of reference groups and audiences play as couples describe their predicaments. This is not the abstract reasoning found among *Shi’a* Muslim clerics (*ijtihad*) (Clarke 2009), but the more prosaic and day-to-day efforts to integrate desires and expectations that are not always consistent with one another. In this view, social life, and by extension ethical life, are ongoing projects in which individuals and groups attempt to persuade one another of the self-evidence, correctness, truth, authenticity and wisdom of one way of living in the world over another. As Carrithers puts it: ‘in any moment of interaction, some act to persuade, others are the targets of persuasion; some work, others are worked upon’ (Carrithers 2005: 580). In discussions about infertility and whether certain courses were morally acceptable or not, it was noticeable how couples readily invoked absent others and imaginary audiences for their actions and even for their thoughts. This dynamic and processual view of social and ethical life draws into question the view of culture as a repertoire of codes and rules to be followed and focuses instead on the day-to-day work of creating the appearance of stable and structured systems that people can inhabit with a reasonable degree of order and predictability. The phenomenologist Alfred Schütz characterised those who are

directly engaged in this process as consociates or those with whom an individual is in ongoing face to face relations (Schütz 1967[1932]). Of more relevance for the argument developed here however, Schütz identifies an important role for those who lie beyond immediate experience. These are the audiences and publics who are outside the immediate social world (contemporaries), those who went before (predecessors) and those who it is imagined will come after (successors), all of which play their part in enabling persons to arrive at ethical positions which are felt to be consistent with prevailing social and cultural values.

In Pakistani Muslim accounts of ARTs, we might thus identify a range of audiences that couples feel inclined or possibly obliged to address in their accounts. Bakhtin's dialogism is useful in capturing the dynamic at work; utterances are characterised by their 'addressivity', that is, they are directed towards specific audiences. They also are marked by their 'answerability', that is, they anticipate certain answers and responses in the move towards a sense of ethical responsibility for actions taken or about to be taken. Following Schütz we can readily see such dialogues taking place with consociates: family and kinship networks, the local community and wider networks in the UK and overseas accessed directly or with the help of new and powerful information and communication technologies. However, there are also wider referents beyond the contexts of face-to-face communication. Schütz's contemporaries are evident in references to the wider Pakistani diaspora and communities back home. We might also include here new contemporaries such as the medical profession and a variety of educators whose influence is evident in people's cogitations.

Predecessors appear regularly in references to parents and grandparents here and abroad. Successors occupy a particularly powerful place in this account for they

are the wished for progeny that will continue the lineage, uphold the religion and, as future moral persons, honour their parents and their predecessors. Thinking about the role of audiences in this way is helpful in illuminating the complex operations that underpin the making of moral justification and consensus around the use of assisted reproductive technology to address childlessness within this and other communities. However, viewed in this way there is a strong presumption of convergence. In the face of contention and contradiction, we can identify a strong pull towards vernacularisation, that is, an optimisation and accommodation wherein conflicting values and possible courses of action are reconciled such that statements of the ‘X is allowed in Y’- kind can be made and, moreover, gain currency (Simpson 2013).

However, what we also go on to describe here is the way in which families and individuals when faced with reproductive crises and dilemmas also formulate strategies and responses that unsettle presumptions of optimisation. Indeed, some responses do not align with expected audiences and suggest conflict and the possibility that new audiences are featuring in the process of moral reasoning. For example, our interviews revealed instances where consociates in the form of family and community have been actively ignored as individuals choose to work against the grain rather than with it in order to shape their own moral justification and rationale for decision-making. These are important dialogical moments in response to ARTs. They are akin to the ‘moral pioneering’ described by Rayna Rapp in her study of amniocentesis in a US hospital (Rapp 1988, 1998). Her work describes the way in which foetal testing raises novel ethical dilemmas for those presented with the option of testing. She shows how these dilemmas are then worked through by women and men from a variety of class and ethnic backgrounds. The combination of patients’ familiar moral beliefs and values brought to bear on wholly novel ethical challenges

led Rapp to characterise these women and men as ‘pioneers’ of a sort; leading the way on behalf of their own communities into unfamiliar and often difficult moral terrain (also cf Williams et al 2005).

In the account which follows we present examples of ‘addressivity’ and ‘answerability’ evident in the accounts of Pakistani Muslim ART users. We also highlight instances of moral pioneering, triggered, at least in part, by their engagement with IVF. We go on to conclude that moral pioneering may not just be about accommodating new positions in relation to existing values but also aligning with new ones and particularly the emergence of reproductive privacy as of primary importance in decision making.

### **Researching Moral Worlds**

The methodological approach we took was in many respects conventional. The fieldwork was carried out mostly among Pakistanis living on Teesside, a heavily industrial conurbation in the north-east of England. The migration of Pakistanis to this region has followed a well-established pattern. Throughout the 1950s and 1960s, single men found their way to the UK ready to fill manpower shortages in manufacturing industries. The remittances sent home did much to alleviate the poverty of the villages they had come from and also enticed others to make the long journey. Many migrants found their way to Teesside, where opportunities in steel, chemical and other heavy industries were widely available and wages were relatively high (Beynon et al 1994). Drawn by a nucleus of established male earners, relatives and friends arrived in Teesside, with many coming from the Mirpur region of Pakistan. Throughout the 1960s and 1970s wives, parents and siblings were brought

over and the community consolidated, expanded and ‘settled’ (Iqbal 2009). It was in this community between 2007 and 2010 that much of our research was carried out.

In the first phase of fieldwork, 65 Pakistani women and 23 men and were recruited from community centres and government centres supporting parents and children (Sure Start) with the aim of eliciting views on family formation, infertility and how people deal with it in social and medical terms. In phase two of the study we focused on men and women who had direct experience of infertility treatments (six couples and three individual women). Interviews were informal and wide-ranging, and were conducted in English, Punjabi or Urdu, according to respondents’ preferences. The snow-balling technique used for this phase of the research took us further afield with two interviews being conducted by phone with IVF users resident in London and Bradford. We adopted a life history format, encouraging participants to narrate their marital and reproductive lives in chronological sequence. Participants were re-interviewed after a period of some months, to follow up on new developments in their lives and reproductive careers. In addition, participant-observation was carried out in a reproductive health clinic used by the Pakistani community on Teesside and additional interviews carried out with clinicians, embryologists, nurses, social workers and GPs. The materials used in this article are drawn predominantly from phase two of the study, that is, from in-depth accounts of the experience of infertility and the use of ARTs.

Elsewhere we have analysed this dataset in ways that might be thought of as sample-based (Hampshire et al. 2012a; b), that is, as qualitatively derived data that has the character of separate individuals expressing a view on, or giving an account of, particular issue. In effect there is a piling up of views to see which vectors are the strongest. This is what Geertz has referred to as ‘extensive’ data collection and



analysis (Geertz 1983). In contrast, the approach we develop in this chapter is ethnographic and ‘intensive’ and enters into the complex traffic in ideas about culture, identity, continuity, boundaries, remembered pasts and imagined futures that feature in British Pakistani Muslims’ accounts of reproductive challenge and its solutions (Hampshire et al 2012c). More specifically we want to understand the ways in which people participate in one another’s responses to the predicament of infertility over time and how their actions and assumptions are shaped with reference to others. Important in this regard was information collected in the four focus groups that we conducted in community centres. On the occasions when contentious topics were raised in these fora it was clear that there was a certain amount of unease about airing discrepant views for an external audience. This public pressure for views to converge around community norms was in contrast to the variability we encountered when discussing issues of infertility and its solutions with individuals and couples on their own. As we demonstrate, the value of an approach which draws on perspectives derived from a variety of settings and circumstances is particularly important where concerns raised fall into the realm of ethics – ‘how should I live?’ - and, furthermore, in understanding the way that the engagement with ARTs is itself part of a process which enables this question to be posed in the first place.

### **ARTs and Pakistani Muslims**

Amongst Muslims the exhortation to reproduce is well known. In the Hadith, the series of texts which provide commentary and clarification on the Quran, it is stated: Marry those who can bear children. I will be pleased if you increase the numbers of the *umma* (Muslim community). Indeed, the procreative potential of women is seen

as integral to their status and the regard with which they are held within Muslim society (Serour 1995). However, as the essential binding agent for a number of ethnic minorities in the UK, Islam is seen as being undermined by a predominantly secular and secularising society. For many, values of familism and procreativity underpinned by religious belief and practice are felt to be under threat and in need of support and preservation (for example see Bari 1992).

Against this backdrop, the ways in which ARTs are currently being taken up within the Pakistani Muslim community suggest that there is considerable ambiguity: ARTs are welcomed but at the same time they are the object of suspicion and concern. On the one hand, ARTs are welcomed because they touch on the powerful and pervasive desire to have children, and offer solutions to a condition that blights public and private lives. In religious terms, the use of ARTs is easily lined up with teachings in the Quran which explicitly encourage treatment for infertility (also cf Inhorn 2003b) and, providing that gametes are taken from a husband and wife, then both *Sunni* and *Shia* traditions are broadly permissive when it comes to IVF (Inhorn and Tremayne 2012). This was broadly speaking the consensus among our informants, their religious leaders and, importantly, clinicians they came into contact with who were themselves practicing Muslims. ARTs were to be welcomed because, on balance, reproductive imperatives far outweigh any ethical qualms that there might be about helping couples become parents. As such, ARTs offer a response to the particular needs of this community when it comes to the prevalence of primary infertility.

Yet, ARTs also address fertility issues arising from pressures of a more general kind. As is the case for many couples, reproductive disruption is situated within wider concerns about morality, relationality and how to live with the economic

and social demands of contemporary social life. Many of the women who spoke to us about their experiences of IVF made reference to issues of lifestyle and particularly concerns about diet, fitness and weight loss that had been raised during treatment. These concerns originated directly in the comments and advice of doctors – ‘I’ve been told they won’t do IVF for me until I lose another 10 kilos in weight or something, which is an issue in itself ‘(W201)<sup>1</sup> - as well as from a wider tendency to associate reproductive fortunes with healthy living. However, such exhortations are not always trusted and other forms of reasoning come into play, as the following example illustrates:

... because we are trying for a baby that is why I have a little bit more knowledge because I look on the internet and the papers as well, you see IVF recommendations in this country (ie the UK) are higher than any other Asian countries... the babies born are a little bit less (in size) and lots of people suffer with these problems. The doctor did explain to me about the drugs and good food and things like that and no matter how many months I eat good food, and they say ‘you eat this one and this one and this one’. In Pakistan there are poor families and they eat only chapatti and these are very very poor people and they can’t afford good food or anything and they have ten children or thirteen children ...()... I have been living in this country for ten years but people are more miserable here... this is a major cause to make the sperm levels go down.  
(W314)

In addition to concerns about food and emotional wellbeing, links were also made with the pressures of organising family life amidst aspirations to study, work and

achieve economic independence. Despite such pressures, the messages from parents and older relatives all point to reproduction as the primary imperative for a newly married couple, resulting in the need to satisfy dual and often conflicting expectations (cf Shaw 2000, 2001). It is in this context that the use of reproductive technologies are being contemplated by couples and cultural orthodoxies made the subject of reflection.

That these technologies allow the possibility of planning family life according to different priorities and timetables is only one aspect of the challenge for young Pakistani Muslims. ARTs also betoken a new kind of threat because they are associated with practices that are antithetical to both Islam and traditional Pakistani kinship. With ARTs come repertoires of possibilities which are profoundly challenging: using donor gametes and embryos, creating families that have parents of the same sex or in which a father is absent, discarding embryos because they are superfluous to requirement, using surrogate mothers and so forth. Hearing of such practices, let alone actually carrying them out, raises concerns because they draw attention to sexuality, family arrangements and reproduction as the subject of choice rather than as incontrovertibly given and in so doing appear to threaten traditional values and structures. Rules about adultery (*zina*) maybe violated, honour (*izzat*) become threatened and people end up 'spoilt' (*kharaab*) just as they are seen to be in many other parts of British society. Furthermore, engaging with novel technologies to address frustrated desires to reproduce is to be drawn into a knowledge and understanding of one's own body, and, more significantly, the body of one's spouse, that goes beyond previous levels of understanding. Whereas couples may simply want a solution, the way in which the treatments are presented typically involves some level of biological commentary, explanation and an expectation of dialogue around

sensitive topics. Couples may thus be drawn, often less than willingly, as ‘moral pioneers’ into the moral and relational framing of ARTS in the UK setting. In the next section we consider this process in more detail and how, in moves towards justification and acceptance of their actions, a variety of addressees come into view for these couples - the Islamic community, families, doctors.

### **Arguing About ARTs**

In our interviews, couples from phase I of the study were mostly in the happy position of reflecting on reproductive disruption and its treatment in the lives of others rather than in their own. For these couples, Islam and what might be thought permissible and not permissible was regularly invoked and often with relatively clear parameters: IVF is permissible within Islam providing a couple only use their own gametes. This view is captured in the following extract from conversations recorded by Mwenza Blell during a focus group at a women’s centre. In discussion, consensus eventually settles on just what is permissible within Islam. In the extract, the first woman has raised the issue of IVF in reference to a close relative who is having difficulty becoming pregnant:

Woman 1: ... because she is not very big, you know, I tell her, ... ‘you make a test tube baby’ and she says, ‘No, my uncle don’t like it because in our religion they think it’s *haraam*’.

Woman 2 (interrupting): It’s not allowed, yeah, it’s not allowed in our religion.

Woman 1: It’s not allowed?

Woman 2: But some people do, but it's not allowed in our Islam.

[The room gets loud with people's comments]

Woman 2 continues: If we study our Islam, it's not allowed.

Researcher: Which part is not allowed?

Woman 1: Because if they think your husband, you know, his eggs (sic), it's all right then God give it. They, they make some other man's eggs and giving it, I think.

Researcher: And that's the problem?

[General agreement]

Woman 1: It's not *halal*.

(Focus group at Women's Centre)

In other words, 'what is most at stake' to use Kleinman's terms (1992:129) is not so much the practice of IVF per se, but an evident suspicion that 'they' – a predominantly Caucasian and non-Muslim health service – will use other people's gametes to achieve a pregnancy. Notwithstanding such concerns however, the technologies, if used in accordance with Islam, were accepted by most of our study participants as being a legitimate means to reduce the potential need for adoption, which many felt was a somewhat ambiguous practice within Islam. Most importantly, they were seen to enable couples to avoid the evident catastrophe of childlessness.

Among those interviewed in phase II, however, all had experienced reproductive disruption and in trying to resolve this problem had engaged more intimately with the moral complexities of IVF in relation to Islam and Pakistani norms regarding families and relationships. For these couples, reflection on these matters revealed tensions and a need to clarify and justify why certain positions were being accepted or rejected. For one man, contemplating ARTs led him to speculate on the relationship between religion and culture and the emergence of a clearly justified position on ARTs. In his view, this position was dependent on education and reference to scripture rather than the vagaries of 'tradition':

I honestly think it's lack of knowledge really. To be honest with you that's the major thing: my grandparents from my mam's side and my dad's side, they weren't educated ..(). They were lacking in the knowledge and even with religion, the religion was there but it was more a culture and it was what people said, so that was a major impact as well and with my parents' generation we got more into religion than listening to what our uncle said down the road or what their grandma used to say ...(). I guess they don't want to make it a public thing; they want to make it a private issue, a private matter because this is where religion and culture and tradition and things get mixed up and some people allow it and some people don't. But religiously that is what we went on and that's what it should be, to be honest with you. It's what people have made up to make religion easy for themselves and really you should be going on religion; it's not hard and everything is written there for you and that's why we got further help from the Imams and they actually showed us a couple of verses from the Koran (H301)

In another instance, the couple had together sought assurances from clerics about their chosen course of action:

We have read up on the religious side to it and he (husband) has talked to people about it in the mosque and, to be honest, we don't believe it's wrong because as long as it's my eggs and his sperm there is nothing wrong with that. It's only wrong when we start using someone else's sperm or if I use somebody else's eggs - that's when it's wrong, so we are all right with it and hopefully we are doing the right thing. It makes sense as well and we are both using our own stuff; it's just we are not doing it the normal way how people do it, we are getting help. (W302)

In this case, it is interesting to note that the woman actually raised the question of whether she should pursue IVF treatment at a local community centre and the women there said 'no', it was simply forbidden (*haraam*); she felt that they were simply not prepared to discuss the matter. The couple reported that they had had more success with their local Imam, as well as one consulted back in Pakistan. Both Imams reassured them that their actions would not violate Islamic law.

Imams were not the only source of advice when it came to reproductive decision-making and Islam. In areas where there are high densities of South Asians, it is likely that some members of the medical profession will also be Muslims and widely known will be known as such by the Muslim community. The couple quoted above readily acknowledged that they used their doctors in this way:



Not that there is nothing wrong with having doctors from a different religion or a different background, but it just helps when you are the same religion. It helps because if I have a query or there is something I am not sure about. I can go to my doctor as well and I can ask my doctor, 'this is what I am worried about and what is your judgement and your opinion on this' and I've got a choice of that as well, and that helps. (W302).

The doctors we interviewed all shared stories of how they had indeed been called upon to give advice about what steps would be permissible within Islam. Some gave their advice freely and in ways that might be thought of as instituting orthodoxy in the guise of medical practice, while others were more reticent:

I can't be in both sides: I'm a professional, I just give them a medical opinion. If they need they go to their own imam, or whatever .... I wouldn't (give an opinion), that is personal. And even if they ask 'you are you Muslim?', ..(), I would say 'yes', but 'what is your opinion', I'd say 'I can't give you, I'm not allowed, it's not my... Even if you ask me in the mosque, if you met me in the mosque and asked me, I wouldn't give you advice because I know you are a patient and I'm a doctor.' I wouldn't. 'I will pass you to a religious person and then you ask'. And I'm sure people appreciate that when you tell them. Because some of them, they come and say, 'We need a donor, we accept donor.' I say 'That's fine'. 'But is it *haraam* or *halal*?' I say, 'I wouldn't tell you, just go and ask'.

(Consultant in reproductive medicine)

At the other end of the spectrum however, some of the more educated and cosmopolitan informants paid little attention to the role of Islam in shaping their decisions. One informant spoke of Islam's 'image problem' and the way in which Islamic conservatives were typically elderly, male and bearded. The idea that they should in anyway interfere with private decision-making about reproductive matters was thought to be not only inappropriate but reprehensible. She described her relationship with her father, whom she considered 'very Islamic', as a continual source of tension. Her education, independence, choice of a white partner and bearing of children late in life through IVF were all characteristics she felt he considered to be very 'un-Islamic' by him.

As these examples illustrate, there is often a powerful conjunction of Islamic and family norms which translates into a formidable pressure for Pakistani couples to conceive early in their married life (Hampshire et al, 2012 a; b). As the women at the focus group demonstrate, they operate not only with immediate face-to-face relations in mind (consociates) but also, in Schütz's terms, a variety of contemporaries and predecessors. Together these make for influential audiences whose opinions, actual and imagined, play an important role in shaping attitudes and practices where infertility is concerned:

Woman 1: Our people, they start, if you're a little bit late, they start...'

Woman 2 [interjecting]: It's mainly outside of the family, people are saying what's wrong with her? what's wrong with him?

[The room breaks into loud conversation about this topic.]

Woman 1: The in-laws talk a lot if the baby is premature; they say the mother is not healthy. I was very healthy and they were already talking after two months about me not being pregnant.

[Focus group at Women's Centre]

The importance of families, and women in particular, in shaping reproductive decision-making is further corroborated by a Pakistani GP who we interviewed:

I think you have to convince them sometimes that [folk remedies are] not true and that we should go ahead with the medical treatment. But again, as I said, that influence it comes from the in-laws or their own parents. Mother or mother-in-law has said something ..().. . Dad tends to get involved a lot less I think on the fertility side of things I must admit.

(General Practitioner)

And later in the interview:

‘Some do [believe in folk remedies] even though they have been born and brought up here, I think it's the parent influence, the Mum and Dad think that way. What Mum thinks, so that it is passed down, but certainly the ones from Pakistan they will have that concept.

(General Practitioner)

This familial concern and interest is thus not just confined to relatives in the UK. Reflecting on his visits to Pakistan, one man revealed how questions about offspring tend to be high on people's agenda: “The first time you go there and you meet the

family it will be, “‘Are you all right? How was your flight out? Do you have any children?’ It’s the third question.” H301

Whether for biological reasons or because of conscious decisions to delay parenthood (see also Hampshire et al, 2012a), the evident absence of offspring inevitably becomes the concern of a wider circle of family members and there is strong desire to ‘please’ parents. However, the ways in which these problems might be overcome leads couples into areas of ambiguity and contingency:

My parents’ parents, my grandparents, they were really strict about [marriage] and, to be honest, I don’t think they would be happy with us doing the IVF. And my parents, their generation I think they would think about it, but be two minded because their parents wouldn’t be happy but obviously with us now it’s changing. With each new generation things are changing. H302

However, this man’s version of gradual but inevitable change across the generations masks some of the tensions that arise on the way. A paradox which we return to later in the chapter is that of a culture of inclusion and intervention among relatives on the one hand and, on the other, technologies that have the potential to redraw the boundaries of public and private life thereby isolating and separating couples. This issue was again one that exercised the women in the focus group – should couples tell others that they are pursuing IVF treatment? The following dialogue was triggered by the comment of a woman who said that despite the expectation of family involvement in reproductive decisions some people do IVF anyway:

Woman 1: They don't tell anybody; they hide. I tell my auntie, "Do and hide" but she said, "No, your uncle don't like it, he's very strict".

Researcher: Are these decisions for the husband or wife?

Woman 1: Both

[Several other people say, 'Husband']

Woman 1: Husband, but it's both, you know, the stricter for husband, you know, they asking, my husband always asking me, he's very friendly, any decisions he asks me but mostly people, you know, they decide.'

[Focus group at Women's Centre]

But, lest we get carried away with the idea that audiences are always there and have to be taken into consideration, for at least one Pakistani-born couple we interviewed, the issue was a lack of audience. The burden of the 'pure' relationship, that is, one in which couples make their own decisions on such serious questions, weighed heavily on them: "Back in Pakistan, there are so many other people like aunties, your dad, your mother; they are caring, but in this country you are a couple (laughs)." H 204.

Apart from family and community, an important audience for couples is the medical profession itself. As we have already seen, Muslim doctors play an important role in advising on the morality of certain courses of action. What doctors think is important to couples, even though on occasion the boundaries between technical and moral intervention become blurred. For some patients, this aspect of their intervention was the subject of criticism and particularly where information was concerned. One of our informants (W201) spoke of the 'god complex' in which doctors, typically male,

could exercise enormous power over women who were likely to have little understanding of the treatment regimes they were embarking on. This woman described her experiences in a London clinic. The Muslim doctor she was consulting established that she had been sexually active before marriage. In her view, the brusque treatment she received throughout the consultation and the rough handling during a subsequent internal examination was not unconnected to this revelation. In another instance, a woman claimed that despite her requests for egg donation, she was told that, as she was a Muslim, this was not allowed (W316).

Where language and education were barriers to effective communication between doctors and patients on Teesside, these problems were considerably exacerbated by suspicion about the medical profession. For one couple interviewed, there was an abiding concern about the quality of treatment they had received for the woman's chronic menorrhagia and underlying fertility problems. Failure to address this problem for over a decade gave the man grounds to believe that, as Pakistanis, he and his wife had received inferior medication and treatment from doctors who were corrupt, incompetent and uncaring. His anger and frustration in the interviews was palpable and brings home the extent to which ARTs require technical and communicational competences as well as moral ones:

We can't do anything else because we have no money, we have no skills. For these kinds of things you need skills and only me and my wife... I can't write my name or my address or date of birth... (H315).

### **ARTs and Couples as Moral Pioneers**

The emergence of companionate and nucleated family forms among South Asians living in the UK has been documented by a number of researchers (Harriss and Shaw 2009, Ahmad, Modood et al 2003 and Shaw 2000 and 2001). Education, prosperity and growing acceptance of liberal values has, for many South Asians, led to a growing convergence with wider patterns of domestic organisation and gender equality within the family in the UK. Indeed, normative pressure for what Giddens has referred to as ‘affective individualism’ is evident in all aspects of contemporary daily life (Giddens 1992, also see Beck and Beck-Gernsheim 1995). In the accounts of reproductive disruption we collected, the engagements with ARTs features as an integral part of this wider trend. Moreover, as we go on to argue, engagement with ARTs is not merely symptomatic of processes of change in this community, it is constitutive of them. It is part of a processual adjustment in which accepted roles and relationships are challenged and changed as couples embark on new possibilities for their domestic and conjugal arrangements. Engagement with ART makes its own contribution to this change as it can bring into question assumptions about patriarchal control and raise questions as to what is choice rather than chance. It also challenges what is thought of as public, private and indeed secret. It is in the context of ARTs that new orientations are set for husbands and wives in relation to what it means to be a couple and what their mutual expectations might be.

For many of the couples interviewed, their eventual resort to IVF was in some senses prefigured in the choices that had been made earlier in life and with this came a deviation away from the views of earlier generations (see also Hampshire et al, 2012a). In the piece of dialogue which follows, it is interesting to note the way that the man interviewed introduces the critical voice of his predecessors.

Wife: I really didn't want a child at a young age because we know that after two or three years then we would have a baby.

Interviewer: Did you have that idea?

Husband: That's pretty much what I wanted as well because I was still at Uni and I didn't have a job. I really couldn't see how we could adjust to a child without having a regular income and I don't want to ask my dad to help out because it's my child; it's not really his responsibility. And that's how I stand as well. ...()... I think it's more the older people, that generation that are now about sixty or fifty plus, they are the ones bringing from their generations all the ideologies that they have and they are still having, 'You have no children, you have to have children.' But it's like now, when I get to fifty or sixty plus, my outlook on things will be different. I'm different and time changes, doesn't it? Because I see other people who are in their forties and they haven't been saying this and they say, you know, 'You young people take your time, you want to get a bit secure first don't you' and all that, but older people, different age or higher age, they are more, 'No children, you should have had at least four by now' – seriously! (laughing) (H&W 301)

This couple had set themselves against parental expectations of a pregnancy early in marriage but then later found themselves facing unwanted reproductive delay with resort to IVF the obvious remedy. Similarly, one of the more cosmopolitan IVF users we interviewed put it as follows:



I think you're kind of conscious of the biological clock ticking, anyway. So for me I'd done my travels, I'd done my career, I'd done my business, you know, sort of aspirations as well. I'd achieved all those things and for me this was my next chapter of my life (W201).

The respondent was a Pakistani-born woman in her late 30s who had been educated to Masters level in the UK and contracted a 'love' marriage. For her, the prospect of 'ostracism' by her family and community held little threat when it came to making decisions about marriage and the timing or methods of family formation. Her use of IVF followed the natural birth of her first child and difficulties conceiving a second at the age of 35. For this couple, using IVF came as part of a wider pattern of options and influences shaping reproductive decision-making: the National Childbirth Trust, health and fitness regimes, home-birthing groups, the internet, and consultation with Asian and non-Asian friends and colleagues facing similar challenges of balancing professional and domestic imperatives. Resort to IVF had little to do with any simple fertility drive but was being harnessed with life-style and a particular aesthetics of family firmly in mind (see also Hampshire et al, 2012b). It is not surprising to learn that this couple were prepared to countenance the other options that ARTs make possible, such as embryo-freezing and egg donation by a sister, in order to have more children at a time of their choosing.

For couples with a more conventional biography, and particularly those who had contracted transnational marriages, IVF was typically used to overcome fertility problems that had delayed early pregnancy. In these cases, the burden of intimacy which ARTs imposed was often greater than for couples who had both grown up in

the UK (cf Charsley 2005). For men in particular, many of the assumptions implicit in the treatment process challenged their ideas of appropriate male roles in relation to women. In a culture which has traditionally attributed reproductive failure to women, a focus on a husband's possible shortcomings was often unwelcome. This response was evident from accounts of some husbands' reluctance to under-go exploratory tests and possibly to receive medication or treatment. A factor here was pressure from in-laws, quick to attribute blame.

They (in-laws) were putting pressure on me. I thought 'maybe it is something wrong with me' and stuff like that...so I went to the doctor and I had tests and he goes, 'You're fine' and my doctor, you know, I had him for life and I know him and he said, 'You had tests and everything's fine your bits and bobs are working fine ....' They (in-laws) still thought it was me at the time.

Eventually this woman asserted her views about their predicament in no uncertain terms:

At last I said, 'Right, after this I am not doing crap all.' I put my foot down and told him, I said, 'I don't give a shit what they say.' I said, 'I'm not taking them (the tablets), it's my body.' I said, 'There's nowt wrong with my body - it's you.' And I said, 'I can't even actually tell them - you could.' You know what I mean? You can't really tell them, old people, like that, but I could tell his sister, yeah, but not them. And even then I didn't want to tell her, I never told her, ... and I said, 'I'm not taking any more of this crap, I don't care what they say.' Do you know what I mean?.... I'm not, I put my foot down and I said, 'I'm not.' I said, 'Like it or lump it, I'm not, sod off.' I said, 'I know the problem's probably you'.

In this case, the man finally succumbed to pressure from his parents and agreed to have a sperm analysis. She stopped taking the drugs prescribed and attention turned to the causes of his low sperm count and she later became pregnant naturally.

The reluctance of men to engage with discussions in which they might be identified as the cause of the 'problem' was one that was readily identified by a GP we interviewed who worked on Teesside:

Usually it's the female who comes in; the males tend not to ...(). What I have found is that, the male, the kind of .... it's not true that they feel that it's me, you know there is some problem, it takes a long long time for things to .... They find it very difficult, that a man could be deficient of something. They find it very difficult to accept for them that there is something wrong with them, that's why a child can't be born. ...()... Again I think there will be a lot of influence from the in-laws. Mother-in-law, she said to do this and the poor girl will do whatever. Because obviously, one thing is that it's not the male's fault.

(General Practitioner)

A desire of some men to opt out of assessment and treatment was often continued into the IVF procedure itself, but here this approach was less of an option, as one of the consultants interviewed opined:

We do get patients who don't turn up for their appointments but eventually probably their nagging wife will actually tell them to come along, or the consultant ... I mean, we occasionally have a patient who says he's been along

to the clinic to produce a sample but when they actually get to the consultation with the gynaecologist, the gynaecologist will find that there isn't any information in the notes, ..(). the patient didn't turn up.

(Consultant)

One GP offered his own views on men's poor engagement with the treatment process. Grooms from Pakistan who marry brides from the UK are likely to be at a disadvantage when it comes to knowledge of the processes they undergo, which he put down to basic education in the biology of reproduction:

Boys who got married to girls from Pakistan who come here, they won't understand but the girls who were born here certainly understand all right you know and I think the majority might. Basically they were brought up in this country, the ones I deal with, so they don't have that difficulty I don't think.

(General Practitioner)

This point was echoed by one of our male informants. For him, being educated was key to a complete acceptance of IVF as an acceptable solution to their fertility problems: "Having education it does help and your minds are more broad and it helps you accept things the way the things work." (H302)

However, acceptance of ARTs and the expectation that couples, not just women, receive treatment unsettles the boundaries between public and private. Amplifying the couple as the locus of primary decision-making through joint appointments, information giving, informed consent procedures and an emphasis on confidentiality, is likely to set them at odds with a wider audience. As one woman

concluded, after reflecting on the likely impacts of family members knowing of her and her husband's predicament:

Yeah, so he is agreeing that community does have a major impact on a person, on a couple, on whatever decision they do take, and this is why we haven't told many people about it. It's not the fact that we want to keep it private but the fact that it will be harder for us and people will comment and some people won't accept it so we have left it between ourselves really (W302).

By contrast with many other aspects of reproduction within this community, there was reluctance among couples to share the details of IVF procedures, even with close relatives. We might think of this as signifying a change in addressivity; a shift between a situation in which the influence of others is predominant in decision-making and the desire to make decisions for and about oneself and each other. In the South Asian context Sariola and Simpson refer to this shift as one from heteronomy – rule by others - to a situation of increasing autonomy or self-rule (Sariola and Simpson 2011). This shift also suggests a re-casting of secrecy as confidentiality sanctioned by the nature of the biomedical intervention (see Shaw, this volume). Indeed, the expectation that a husband and wife together own their reproductive problems is implicit in the approach of the medical profession when it comes to determining IVF treatment regimes. Both are expected to engage with the treatment and, as we have seen, some couples are entirely at ease with this approach whereas others show great reluctance. What is common to all, however, is a tension between the couple-focussed privacy on the one hand and the expectation on the part of kin and community that reproduction is in some sense a public matter. The consequences

of making one's reproductive tribulations widely known was brought home by one informant who described how a couple who were known to have finally conceived via IVF after five or six cycles and over two decades of marriage became a running joke amongst their own family members for having had a baby using 'new technology'.

That resort to IVF could result in denigration by those from whom one might otherwise expect support and understanding in part explains the search for new audiences to affirm the validity of actions taken. Couples themselves indicated their solidarity and mutual affection in the face of the pressures that IVF treatment brings. They also indicated the importance of the role of others facing similar difficulties. When asked what might have helped with a difficult and prolonged encounter with IVF treatment, one woman commented:

I would probably say that maybe there should be some opportunity for parents, prospective parents, to chat to parents who have been through IVF. I am sort of thinking especially those who have twins and thinking about the decision to put two embryos back (W202)

This woman went on to identify the importance of consulting educational materials in books, magazines and on the internet as well as reference to advocacy and self-help groups such as the La Leche League, a breast-feeding advocacy and support group. Significantly, the emergence of a nascent biosociality (Rabinow 1996) around the experience of IVF and multiple birth was instrumental in her questioning aspects of informed consent in IVF and later refusing advice of her midwife over supplementary feeding. Moral pioneering, it would seem, not only set her against her own community but also against the medical profession.

## **Conclusion: Moral Pioneering in Late Modernity**

In his classic account of the fate of relationships under the conditions of high modernity, Giddens charted a path along which individuals in contemporary western societies are drawn (Giddens 1992). Along this route, traditions atrophy and are rejected and the modern condition becomes increasingly characterised by risk, uncertainty and the illusions of choice and freedom. The thesis is a simple and influential one that has played an important part in charting the transformation of relationships, family and intimacy in late modern societies. However, it has had little to say about ethnic minorities nor about the burden that intimacy and reflexivity places on those who find themselves inexorably drawn into it.

In this chapter, we have considered ethnographic and narrative accounts of Pakistanis who, in experiencing disruptions to their desire to become pregnant have resorted to ARTs to resolve these crises. In these accounts are discernible some of the broad outlines of the trajectories that Giddens has written about: the fragility of identities in a pluralistic setting, the move towards de-traditionalisation, the emergence of 'pure' relationships and a growing self-reflexivity focused on the couple as the primary social unit. However, what we have also highlighted are the ways in which ARTs are not merely about individual choices but are rooted in a more complex moral and cultural landscape. This landscape is glimpsed in narrative accounts in which ARTs are the subject of a process of ethical triangulation. Following Schütz, we have identified these points of triangulation in informant accounts of face-to-face relations as well as beyond these in an imagined audience of predecessors, contemporaries and successors, all of whom are addressed and occasionally given voice in our conversations. These accounts suggest a delicate navigation between a number of key reference points - imams, the family, the wider

community, those ‘back home’ and the medical profession. The expectations and influences of these people must all be carefully reckoned and, where possible, reconciled with the desire of women and men to become parents on their own terms. In so doing, these couples find themselves acting as moral pioneers in the way that Rapp has described in the case of amniocentesis, that is, persons who, perforce, must fashion new ways of bringing meaning, justification and validation to their use of ARTs to overcome reproductive disruption.

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### **NOTES**

The figures in brackets refer to the interview transcripts as they have been deposited in the Economic and Social Data Qualidata archive. The prefix ‘W’ refers to wives